

3/19/18

4:08 p.m.

Chapter No. 400
18/SS26/R223SG
aj / tbluc

SENATE BILL NO. 2463

Originated in Senate Liz Welch Secretary

SENATE BILL NO. 2463

AN ACT TO PROVIDE THAT THE UNIVERSITY OF MISSISSIPPI MEDICAL CENTER AS THE LEAD AGENCY, TOGETHER WITH THE STATE DEPARTMENT OF HEALTH, THE DIVISION OF MEDICAID AND THE MISSISSIPPI HEALTH INFORMATION NETWORK, SHALL COOPERATE WITH EACH OTHER IN PREPARING A COMPREHENSIVE REPORT ON THE STATE OF RARE DISEASES IN MISSISSIPPI, INCLUDING THE INCIDENCE OF RARE DISEASES IN THE STATE, THE STATUS OF THE RARE DISEASE COMMUNITY, AND TREATMENT AND SERVICES PROVIDED TO PERSONS WITH RARE DISEASES IN THE STATE; TO PROVIDE THAT THE REPORT SHALL BE PRESENTED TO THE CHAIRS OF CERTAIN LEGISLATIVE COMMITTEES NOT LATER THAN DECEMBER 1, 2019; AND FOR RELATED PURPOSES.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MISSISSIPPI:

SECTION 1. The Legislature finds and declares:

(a) A rare disease is defined as a disease that affects fewer than two hundred thousand (200,000) people in the United States. Rare diseases are sometimes called orphan diseases. There are seven thousand (7,000) known rare diseases affecting approximately thirty million (30,000,000) men, women and children in the United States;

(b) The exact cause for many rare diseases remains unknown. However, eighty percent (80%) of rare diseases are

genetic in origin and can be linked to mutations in a single gene or in multiple genes. Those diseases are referred to as genetic diseases. Genetic disease can be passed down from generation to generation, explaining why certain rare diseases run in families. It is also estimated that about half of all rare diseases affect children;

(c) A person suffering with a rare disease in Mississippi faces a wide range of challenges, including, but not limited to: delays in obtaining a diagnosis; misdiagnosis; shortage of medical specialists who are familiar with, and can provide treatment for, rare diseases; prohibitive cost of treatment; and the inability to access therapies and medication that are used by doctors to treat rare diseases but have not been approved by the federal Food and Drug Administration (FDA) for that specific purpose;

(d) In recent years, researchers have made considerable progress in developing diagnostic tools and treatment protocols for, and in discovering ways to prevent a variety of, rare diseases. However, much more remains to be done in the areas of rare disease research and the search for and development of new therapeutics; and

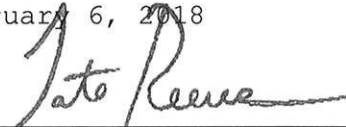
(e) It would be very beneficial to persons in Mississippi with rare diseases and to researchers who are trying to find ways to treat or prevent the occurrence of rare diseases to examine the existing data on rare diseases in Mississippi and

compile it in a detailed report, which then could be analyzed and used to educate medical professionals, government agencies and the public about rare diseases as an important public health issue, and to encourage and fund research in the development of new treatments for rare diseases.

SECTION 2. The University of Mississippi Medical Center (UMMC) as the lead agency, together with the State Department of Health, the Division of Medicaid and the Mississippi Health Information Network (MS-HIN), shall cooperate with each other in preparing a comprehensive report on the state of rare diseases in Mississippi, including the incidence of rare diseases in the state, the status of the rare disease community, and treatment and services provided to persons with rare diseases in the state. The State Department of Health, the Division of Medicaid and the MS-HIN shall provide to UMMC and each other all claims data and patient encounter data relating to the diagnosis and treatment of rare diseases and all related research and documentation relating to rare diseases, which shall be compiled, examined and analyzed in the report. The report shall be presented to the Chairs of the House Public Health and Human Services Committee, Senate Public Health and Welfare Committee, and the House and Senate Medicaid Committees not later than December 1, 2019.

SECTION 3. This act shall take effect and be in force from and after its passage.

PASSED BY THE SENATE
February 6, 2018



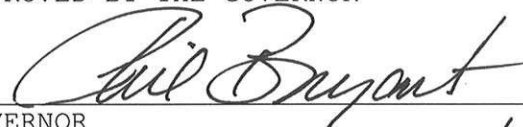
PRESIDENT OF THE SENATE

PASSED BY THE HOUSE OF REPRESENTATIVES
March 1, 2018



SPEAKER OF THE HOUSE OF REPRESENTATIVES

APPROVED BY THE GOVERNOR



GOVERNOR

3/19/18
4:08 pm